

Priority Setting in Action: using web-based surveys



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Funded by NIHR Cochrane Programme Grant (16/114/26)

LIFE CHANGING
World Shaping



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Our partnership



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

www.epilepsy.org.uk

Sally **Crowe**

www.parkinsons.org.uk

Kristina **Staley**

This presentation – how we did it

1 Task & development

2 Approach

3 Analysis & impact

4 Learning

This presentation

We aim to share our experience of

- Thinking through and developing an approach to topic refinement
- Developing web-based surveys and promoting participation
- Reflection on our experience

Our task

Seek stakeholder's preferences for Cochrane systematic reviews:

- **topics** relating to interventions and care
- **outcomes** to used or aspects of care for consideration in the reviews

We call this **topic refinement**

Our NIHR programme grant was awarded to support development of a *specified* number of reviews from 2 Cochrane Groups:

- Epilepsy & Movement Disorders

Development – step 1

I had a think...

Development – process driven

The logo for NICE, consisting of the word "NICE" in a bold, white, sans-serif font centered within a dark teal square background.


NICE

Development – extensive approaches




The Cochrane Tobacco Addiction Group (TAG) Anniversary and Priority Setting Workshop

Development – reference methods




**Guidance note for
Cochrane Groups to
define systematic review
priorities**


Developed by the Knowledge
Translation Working Group on
Embedding Prioritization
September 2019
Version 3




[Click Here](#)



The James Lind Alliance Guidebook
Version 8
November 2018



www.jla.nihr.ac.uk



NIHR | National Institute
for Health Research

1

Development – reference methods

Alcohol-Related Liver Disease PSP Project plan

(For information, a typical PSP completes in around 12-18 months)

Task	Notes	Who is involved?	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14	Dec-14	Jan-15	Feb-15	Mar-15	Apr-15	May-15	Jun-15	Jul-15	Aug-15	Sep-15	Oct-15	Nov-15	Dec-15
Initial awareness meeting																						
	Assess interest in participating/joining Steering Group	PSP Lead/JLA Adviser?	█																			
Hold meeting																						
Steering Group (SG)																						
Scope out SG		PSP Lead																				
Hold preliminary SG meeting		SG/JLA Adviser																				
Agree protocol		SG																				
Recruit information specialist	With input from Steering Group	PSP leader/SG																				
Agree Terms of Reference		SG																				
Website																						
Produce project website	With input from SG	PSP Co-ordinator/PSP Lead?																				
Announce launch of site and PSP		All																				
Survey of patients, carers and clinicians																						
Design survey		PSP Lead/JLA Adviser/all																				
Feedback from steering group		SG																				
External pilot		SG																				
Launch survey		All																				
2-3 rounds of publicity		All																				
Leave survey online																						
Give progress reports to SG		PSP Co-ordinator/Lead/Info Specialist?																				
Close survey		Info specialist																				
Checking the uncertainties																						
Preparation / agreement of taxonomy	With input from SG	Info Specialist																				
Categorisation of submissions	With input from SG	Info Specialist																				
Lumping/splitting	With input from SG	Info Specialist																				
PICO formatting	With input from SG	Info Specialist																				
Removal of out of scope	With input from SG	Info Specialist																				
Checking against SRS and guidelines	With input from SG	Info Specialist																				
Identification of research recommendations	With input from SG	Info Specialist																				
Preparation of long list of verified uncertainties	With input from SG	Info Specialist																				
Preparation of dataset for UK DUETS		Info Specialist																				
Interim prioritisation exercise																						
Finalise who will participate in this stage		SG																				
Agree the long list of uncertainties		SG																				
Agree format of the shortlisting form		SG																				
Issue the shortlisting survey		PSP Co-ordinator/Lead?																				
Send reminder		PSP Co-ordinator/Lead?																				
Collect, collate and rank responses		PSP Co-ordinator/Lead/Information Specialist?																				
Agree final shortlist to take to the workshop		SG																				
Final prioritisation workshop																						
Agree time and book venue for workshop		PSP Co-ordinator																				
Agree workshop format		SG																				
Invite participants		PSP Co-ordinator																				
Book catering etc		PSP Co-ordinator																				
Prepare and send out pre-workshop pack		PSP Co-ordinator																				
Prepare workshop materials		PSP Co-ordinator																				
Chair and facilitate workshop	With other JLA Advisers	JLA Adviser																				
Dissemination																						
Development of research questions		SG/Information Specialist																				
Liaison with research funding organisations		All																				
Lay report		SG																				
Scientific report		SG																				

Dates of Steering Group meetings:

Other Key dates:
 Launch Survey
 Interim prioritisation
 Final workshop

“a typical PSP completes in around 12-18 months”

Development – consider the journey



Development – consider value



Perfect is the enemy of good?

Development – other steps

I thought...

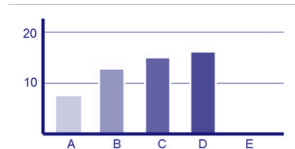
I read...

I shared...

I did...

Overview - priority setting approaches

Technical



Use of existing data e.g. disease prevalence, economic burden, other measures

Scoring and use against matrix of criteria

Gap analysis or identified need e.g. **Guidance** and policy plans, commissioning health services

Systematic review of **existing priority** sets

Horizon and environmental scanning

Cochrane criteria (e.g. downloads) or editorial decisions

Interpretive



Surveys to **generate/ rank/** validate priorities (Delphi or other)

Using 'free text' data to inform above

Creating/enriching scenarios to inform research topics and priorities

Discussion among **informed stakeholders** to generate and or agree priorities; workshops, meetings.

Accessing patient **narratives**, help line data and proxy sources of perspectives

Approach – overview

Developed and piloted a **2 web-based surveys**:

- Epilepsy
- Parkinson's Disease

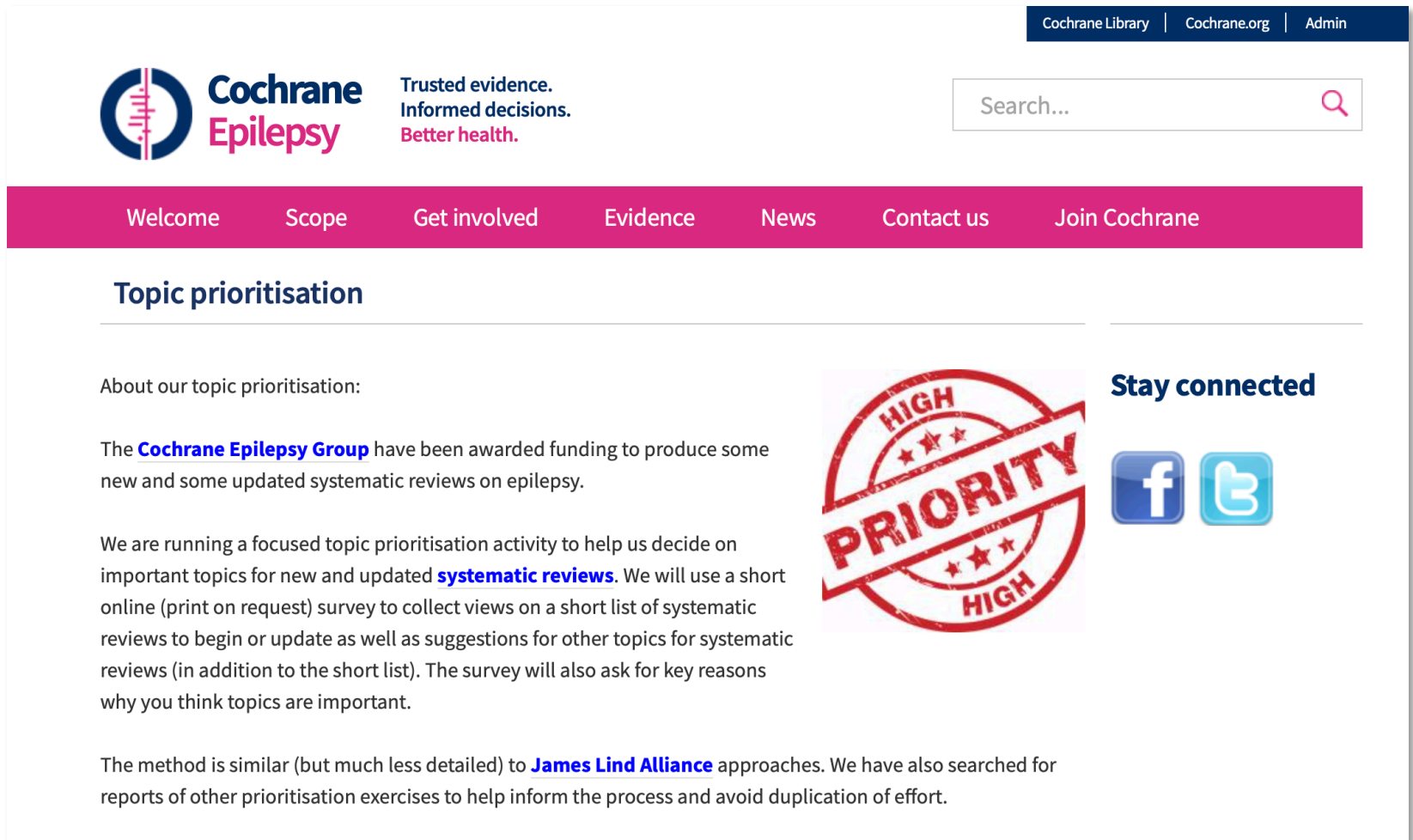
Topic lists from **editorial base** teams

Worked closely with a small **selection** of epilepsy and Parkinson's organisations

Developed a **digital** media strategy to promote the surveys

No workshops or face-to-face meetings scheduled

Approach – promotion (1)



The screenshot shows the top navigation bar with links for Cochrane Library, Cochrane.org, and Admin. The Cochrane Epilepsy logo is on the left, with the tagline "Trusted evidence. Informed decisions. Better health." A search bar is on the right. Below the navigation bar is a pink menu bar with links: Welcome, Scope, Get involved, Evidence, News, Contact us, and Join Cochrane. The main content area is titled "Topic prioritisation".



About our topic prioritisation:

The [Cochrane Epilepsy Group](#) have been awarded funding to produce some new and some updated systematic reviews on epilepsy.

We are running a focused topic prioritisation activity to help us decide on important topics for new and updated [systematic reviews](#). We will use a short online (print on request) survey to collect views on a short list of systematic reviews to begin or update as well as suggestions for other topics for systematic reviews (in addition to the short list). The survey will also ask for key reasons why you think topics are important.


The method is similar (but much less detailed) to [James Lind Alliance](#) approaches. We have also searched for reports of other prioritisation exercises to help inform the process and avoid duplication of effort.

Stay connected




Approach - promotion (2)

- Accessed 'research interested' networks using targeted direct mail:
 - EA 8000 list members
 - PUK 4500 list members
- Our Cochrane groups emailed their members
- Cochrane & partner social media support



PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Research Support Network
 **Have your say**

Hello Sara

We have an opportunity for you to help identify the most important topics for systematic reviews on Parkinson's.

Producing new and updated systematic reviews

The Cochrane Movement Disorders Group are collecting evidence to help inform assessment, treatment and care using an approach called a systematic review. Systematic reviews bring together evidence from existing studies.

Ruaraidh Hill and his team at the University of Liverpool need your help to identify the most important topics for updated and new systematic reviews on Parkinson's.

What's involved?
The research team would like you to [complete an online survey](#) to help them find out more about people's priorities for these reviews.

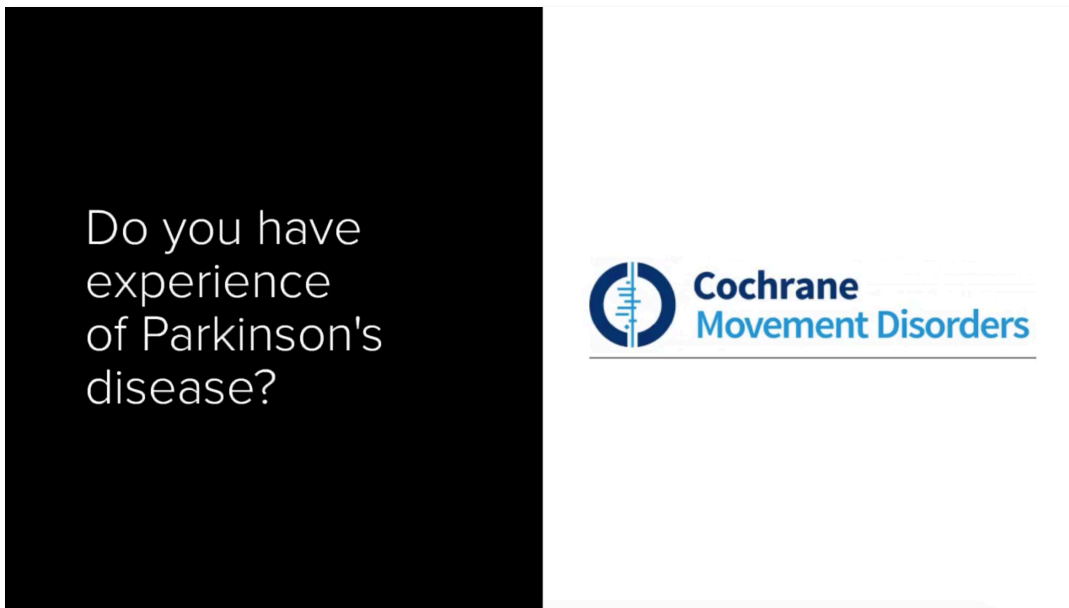
For more information about the background of this research, please [visit the website](#).

How do I get involved?
Please [complete the survey](#) by **Monday 1 October**. The survey should take between 10 and 30 minutes to complete, depending on how much you'd like to say.

If you have any questions about this work, contact Ruaraidh by email (Ruaraidh.Hill@liverpool.ac.uk) or phone (0151 794 5569).

Complete the survey

Approach – promotion (3)



<https://spark.adobe.com/video/LojNYUy3nLoli>

<https://spark.adobe.com/video/Qhc6vEwBg6Eaa>

Approach – promotion (4)



Cochrane Epilepsy

Survey coming soon

Trusted evidence.
Informed decisions.
Better health.



Epilepsy Action @epilepsyaction

Parkinson's UK, NIHR Research, and 3 others follow

The UK's leading member-led epilepsy charity, providing information for the 600,000 people with epilepsy in the UK and anyone with an interest in the condition

Leeds, UK epilepsy.org.uk

Joined November 2008

2,157 Following 25.2K Followers

Tweets Tweets & replies Media Likes

Epilepsy Action @epilepsyaction · 11h

If you're inspired by #GBBO 🍷 to grab a whisk and avoid soggy bottoms, you can change lives by getting together for a tea break to support people with epilepsy! 🍵 Sign up today and you'll get everything you need - epilepsy.org.uk/teabreak



Cochrane @cochraneollab

Following

Have your say! Help @CochraneMDG set the priorities for future systematic reviews of Parkinson's Disease! Survey open to people with experience of #Parkinsons – people with the condition, carers, family members & professionals. buff.ly/2p7VwKS



Cochrane Movement Disorders

5:08 pm · 2 Oct 2018

4 Retweets 2 Likes

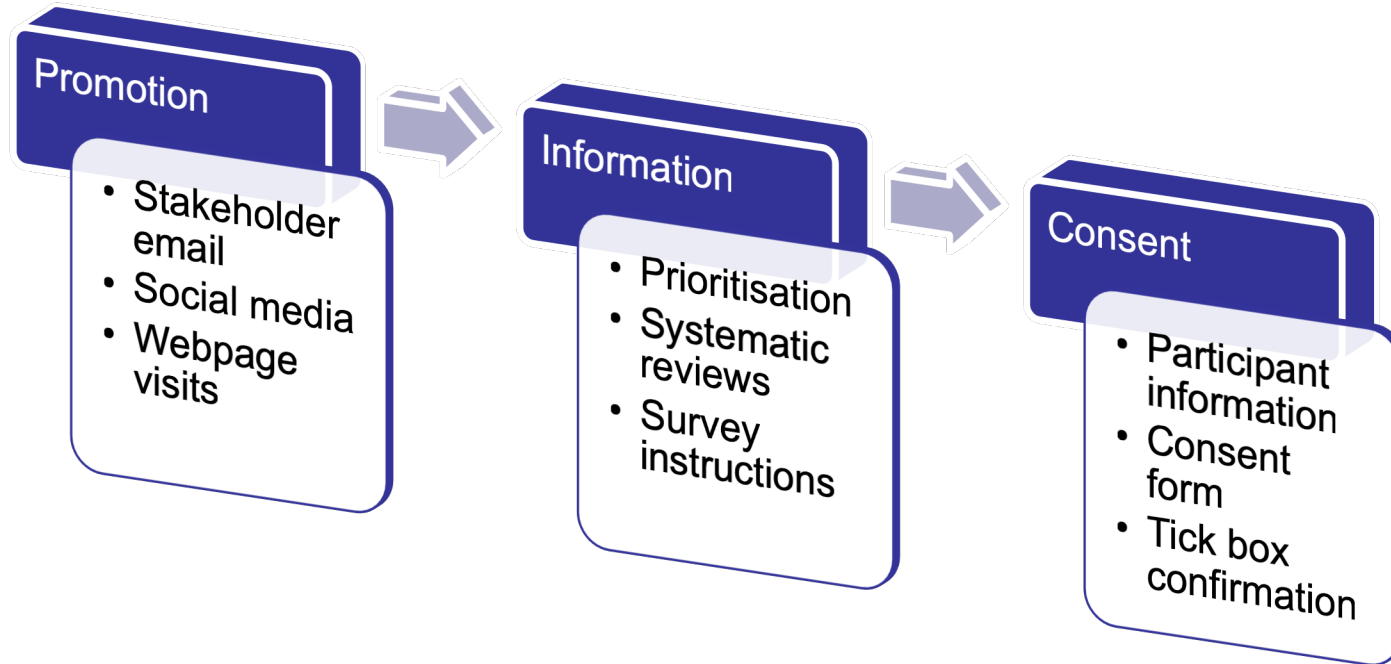
Tweet your reply

Ruaraidh Hill @RuaraidhHill · 2 Oct 2018

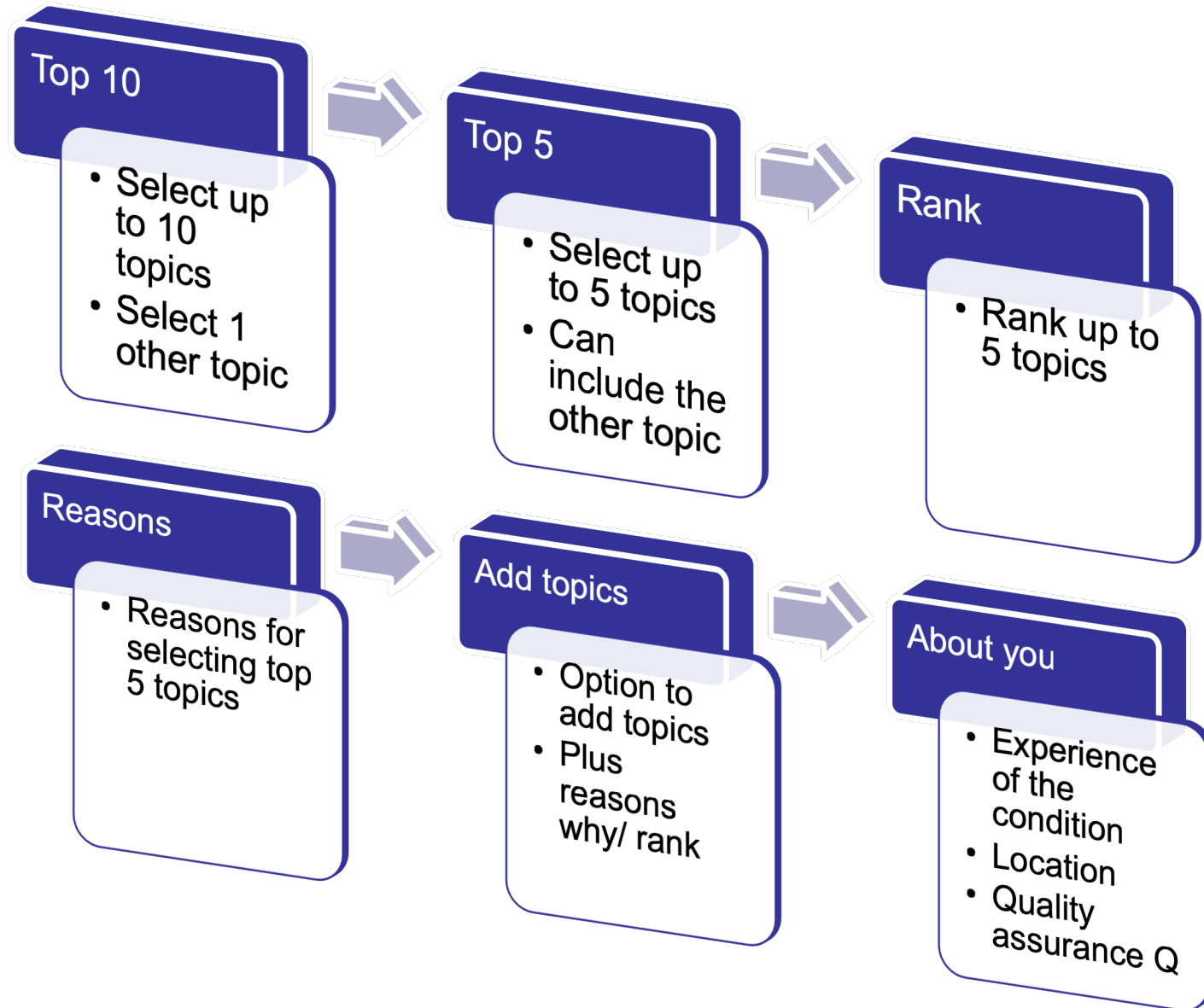
Replying to @cochraneollab @CochraneMDG

Link working well - near to 500 responses, largely people with Parkinson's, sharing priorities for #systematicreviews. With your help we can get over 500! Please RT & See: surveymonkey.co.uk/r/PD_SRPriorit...

Approach – survey structure



Approach – survey structure



Approach - survey introduction



Topic development - Cochrane Epilepsy Group

Welcome to our short survey


In the survey, you will be asked to share your views on **top priorities for research using systematic reviews**. There are 6 steps:

1. Select up to **10 top** topics
2. Select up to **5 top** topics
3. **Rank** your top topics
4. **Tell us more** about your choices
5. **Add** other topics & tell us more
6. About you (optional) & **submit**

Thank you for participating. Your views are important.

The [Cochrane Epilepsy Group](#) asks for your help to identify the most important topics for updated and new **systematic reviews on epilepsy**.

Approach – survey steps




DEMO Topic development - Cochrane Reviews

Step 1 - Your top 5 priorities

Please **read all** of the suggested topics below, then select up to 5 topics you think are a priority for a new or updated [systematic review](#). You can select fewer than 5 topics if you wish. Some topics already have a completed systematic review, but may need updating with a search for new evidence.

*** Please choose up to TOP 5 (five) topics**

- TOPIC 1
- TOPIC 2
- TOPIC 4
- TOPIC 3
- TOPIC 5
- Other topics not listed above - we will ask you about other topics later in the survey




DEMO Topic development - Cochrane Reviews


Step 2 - RANK your top priorities

Please rank your **TOP** topics - rank your highest priority **1 (one)**

- 1 TOPIC 1
- 2 TOPIC 2
- 4 TOPIC 3
- 3 TOPIC 4

Prev Next

Powered by  See how easy it is to [create a survey](#).



DEMO Topic development - Cochrane Reviews

Step 3 - Tell us about your top priorities

Tell us why – Think about the **your top topics** (you may have selected fewer than 5).

- Why are these important?
- What aspect of Parkinson's Disease will the reviews provide evidence about?
- Will the review help answer questions about which treatment or care is best to offer?

Please add **your reasons** why the topics are important in the text box under the topic title.

Tell us more about why these topics are a priority for more research using a systematic review

TOPIC 1

TOPIC 2

TOPIC 3

TOPIC 4

The survey – some features/ functions

General approach

- Mix of closed form, ranking and open form items on topics
- Prioritisation using a **sequence** of selecting:
 - top 10 → then top 5 → then ranking the top 5

*Technical details**

- Used the survey platform's response 'carry forward' functionality
- Topics initially presented to respondents in random order
- Survey split into 'pages' to allow data capture without respondents reaching end page
- Demographic questions at end and deliberately restricted in detail



** WARNING – if you ask me about these,
I will talk your ears off*

Approach – random order, bulk answers

The screenshot displays the SurveyMonkey editor interface. At the top, the browser address bar shows 'surveymonkey.com'. The page title is '*DEMO* Topic development - Cochrane Reviews'. A navigation bar includes 'SUMMARY', 'DESIGN SURVEY', 'PREVIEW & SCORE', 'COLLECT RESPONSES', 'ANALYZE RESULTS', and 'PRESENT RESULTS'. A 'NEXT' button is visible in the top right corner.

The main content area is divided into a 'QUESTION BANK' sidebar on the left and a central editing pane. The editing pane shows a question titled 'Q1' with the text 'Please choose up to TOP 5 (five) topics'. The question type is set to 'Checkboxes'. Below the question text, there are five answer choices, each in a text input field: 'TOPIC 1', 'TOPIC 2', 'TOPIC 3', 'TOPIC 4', and 'TOPIC 5'. Each choice has a plus/minus icon to its right. A 'BULK ANSWERS' toggle is located below the answer choices.

Below the answer choices, there are several settings:

- Score this question (enable quiz mode)
- Use previous answer choices (carry forward responses)
- Add an "Other" Answer Option or Comment Field

The 'Other' field configuration includes:

- Label:** Other topics not listed above - we will ask you about other topics later in the survey
- Display as answer choice
- Display as comment field
- When the answer is left blank, display this error message:** Please enter a comment.
- Size:** Single Line of Text, 100 characters

On the right side of the editor, there are 'Help' and 'Feedback' buttons.

<https://www.surveymonkey.co.uk/r/CochraneDemo>

Approach – carry forward

DEMO Topic development - Cochrane Reviews

SUMMARY → DESIGN SURVEY → PREVIEW & SCORE → COLLECT RESPONSES → ANALYZE RESULTS → PRESENT RESULTS

QUESTION BANK

Search for questions

Recommended Questions

Previously Used Questions

All Categories

Community

Customer Feedback

Customer Satisfaction

Demographics

Education

Events

Healthcare

Human Resources

Industry Specific

Just for Fun

Market Research

Non-Profit

Political

DEMO Topic development - Cochrane Reviews

Step 2 - RANK your top priorities

EDIT OPTIONS MOVE COPY

Q3 Please rank your TOP topics - rank your highest priority 1 (one) Ranking

TOPIC 1

TOPIC 2

TOPIC 3

TOPIC 4

TOPIC 5

[insert text from Other]

Use previous answer choices (carry forward responses)

Choose answers from:

Please choose up to TOP 5 (five) topics

Selected by respondent Unselected by respondent

Add a N/A column.

NEXT QUESTION CANCEL SAVE

NEW QUESTION

or Copy and paste questions

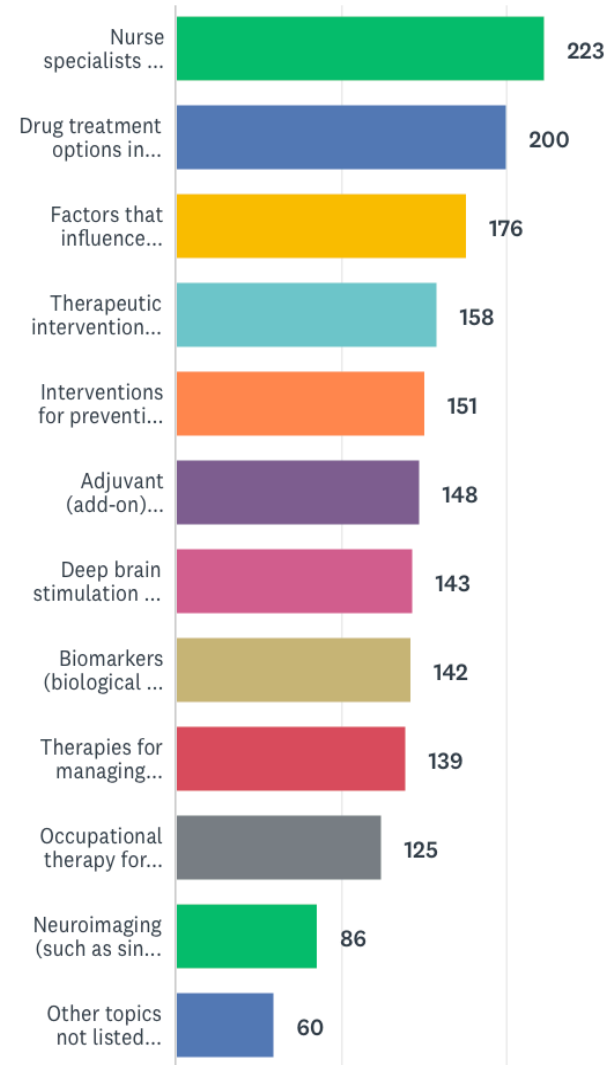
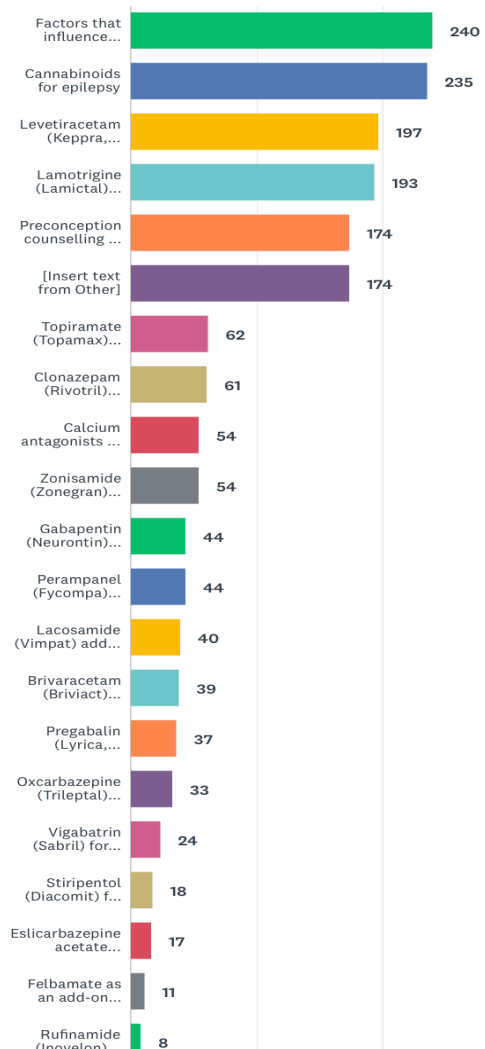
Help Feedback

<https://www.surveymonkey.co.uk/r/CochraneDemo>

Analysis & impact - reach

- Largely UK-based respondents
- Over 1000 respondents:
 - 569 started the epilepsy survey
 - 470 started the Parkinson's survey
- Majority of respondents were people with the condition:
 - 59% epilepsy
 - 78% Parkinson's
- Few responses from professionals

Analysis & impact – top 5 (epilepsy, PD)



Analysis & impact

- Different patterns in responses between epilepsy and Parkinson's disease
 - **Epilepsy** – ‘cluster and cliff’
 - **Parkinson's** – *more* evenly distributed
- Priorities *generally* consistent across top 5 and ranking scores
- Rich information source in reasons why free text
 - Some relatively simple, reflecting personal experience
 - **Epilepsy** – “People are going nuts about CBD, presuming it will work for them and taking any form of cannabis that they can...”
 - **Parkinson's** – “Anxiety has been the most distressing element on a day to day basis of my Parkinson's. Even being unable to walk properly is easier to deal with.”

Learning – Cochrane KT guidance

Governance – team to develop the process



Shortlist by Cochrane groups, with external stakeholder reps. Refinement involved external experts & stakeholder reps.

Stakeholder engagement – external & internal to Cochrane



External: people with lived experience via in email & social media - reasonable numbers & diversity, some health professionals. Internal: via Cochrane group authors email, Consumer Facebook & KT group

Documentation & dissemination



Process & findings to be written-up & disseminated (plus conferences, webinar). Priorities informed programme planning

Currency & timeframe



Current for 2018-21

Learning – REPRISE checklist

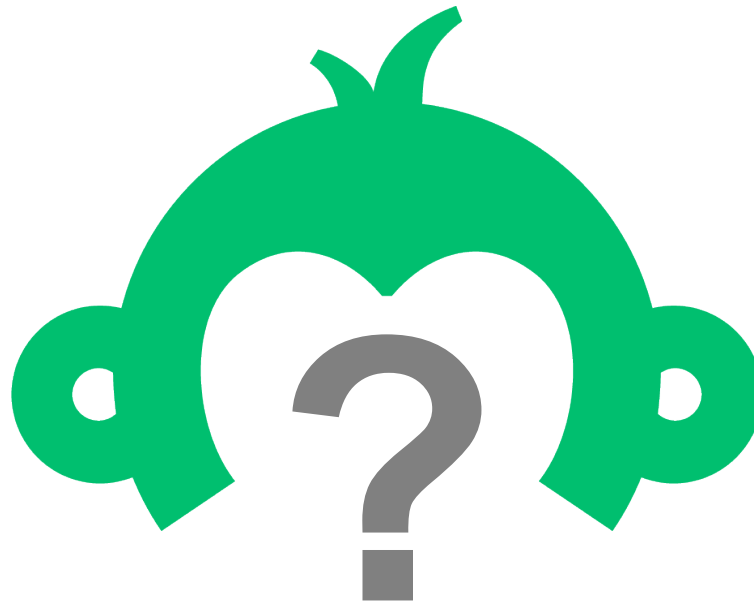
1. **Context and scope** – UK based, interventional questions, SRs, epilepsy and Parkinson’s disease, medium term priorities.
2. **Governance and team** – internal team referred to throughout, could have had more external members, some team members experienced in priority setting.
3. **Inclusion of stakeholders** – lived experience and specialist professionals (limited information), aim for 300 in each survey, no reimbursement for participation.
4. **ID and collection of topics** – previous prioritisation exercises, online survey, gathering topics in addition to set for prioritisation, known unknowns.
5. **Prioritisation of topics** – individual ‘forced’ online ranking, exclusions of other questions yet to be determined.
6. **Outputs** – Epilepsy ranked set, Parkinson’s Disease less distinct priorities.
7. **Evaluation and feedback** – currently in this phase.

Learning – key reflections (1)

- Navigating from ‘gold’ to ‘**good**’
 - Thinking about goals, ‘distance’, support and value
 - Broadly in line with prioritisation guidance
- **Staging** approaches – topic shortlists, web-based approaches, workshops held in reserve
 - Remote approach, but good reach and interactive, consumer driven elements
- **Focused** engagement with a selection of stakeholders
- **Engaging** target audience in testing and improvement of surveys
- Integrating other **topic research** – reasons why
- **Defining** ‘systematic review’ – not easy!

Learning – key reflections (2)

- Managing **information shared** by people with a condition
 - Data governance and legislation – care needed
 - Resource to analyse
- Choosing **digital tools**



Learning – your views...

- In what ways could we have done this better?
- Was the approach **good enough**?
- What would you **want to know** in a report/publication?
- How should we disseminate?
- Is the lack of professional respondents an issue?

This presentation – how we did it

- 1 Task & development
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Declaration of interests, funding and acknowledgements

Ruaraidh	Financial – non personal, non specific interest. Delivered educational workshops on health economics, medicines management and HTA for cancer specialists – unrestricted sponsorship by pharmaceutical industry and industry association (March 2019). Not specific to topics presented. Cochrane author
Sally, Kristina	Received consultancy payment for work on this project
Ethics	Methods and content approved by Health and Life Sciences Research Ethics Committee (3087)
Funder	National Institute for Health Research - Cochrane Programme Grant (16/114/26).
We acknowledge	the 1039 people who told us what was important to about systematic reviews in epilepsy and Parkinson's Disease, our partners and Programme teams in CEG and CMDG



U N I V E R S I T Y O F

L I V E R P O O L

A member of the Russell Group

LIFE CHANGING
World Shaping